This is a repository copy of *Fixed: the science/fiction of human enhancement*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/93435/

Version: Accepted Version

Article:
de Saille, S. (2014) Fixed: the science/fiction of human enhancement. Journal of Responsible Innovation, 1 (1). 142 - 145. ISSN 2329-9460

https://doi.org/10.1080/23299460.2014.882096

Reuse
Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

REVIEW:
Fixed: The Science/Fiction of Human Enhancement
Directed by Regan Brashear. New Day Films, 1hr. <http://fixedthemovie.com>

Reviewed by Stevienna de Saille, University of Sheffield.

The fast-developing discourse of responsible innovation (RI) has mainly focused on emergent and unforeseeably risky new technologies – the genie-in-the-bottle fields of nanotechnology, synthetic biology, and geoengineering, in which mistakes could unleash consequences that may be global, catastrophic and irreversible. Rarely, so far, has RI been applied to biomedical innovations, which are normatively seen as having individual, and largely beneficial, consequences, particularly where their purpose is to restore lost or damaged physical function. Perhaps because biomedicine itself increasingly sees health and illness as a matter of personal responsibility, questions about the potential of therapeutic technologies to also confer beyond-normal abilities tend to be answered with the language of human rights. This framing of enhancement as a matter of individual self-actualization, autonomy, and freedom of choice has too often stifled the ability to give equal weight to the risks posed by dual-use, or by adoption on a collective level. This is the uneasy and quickly shifting terrain of Fixed: The Science/Fiction of Human Enhancement, a new documentary by California filmmaker Regan Brashear.

We have long used restorative technologies – spectacles, hearing aids, mobility tools – to overcome impairment. So why not improve these to provide a longer range of vision, or the ability to hear at higher frequencies, rather than simply compensate for loss of function? Aren't exoskeletons, cognitive drugs, brain implants and bionic limbs merely the next phase of a trajectory we've always been on? At what point do these tools go beyond their restorative purpose, and begin to reinforce structural inequalities by redefining "normal" itself? Is the desire to improve performance or appearance only a matter of individual self-fulfillment and choice, or will it also become a matter of economic survival in an increasingly brutal, competitive environment -- whose increased brutality is simultaneously the excuse for, and the result of, normalizing the desire for technologies that allow us to go beyond species-typical function? Will those of us who remain merely ordinary become the new disabled if we cannot or choose not to follow such trends? Those interested in

considering these and other questions of democratic governance of biomedical science from a disability perspective should particularly find this short, one-hour film of great interest.

Fixed begins with a young woman in a flower-print dress and sunglasses floating ethereally alongside an underwater coral reef. Already something of an unexpected juxtaposition, as the camera pulls back we see something even more unexpected – that she is making this journey strapped to a wheelchair with plexiglass fins. This sequence – along with the invention of an actual, jet-powered underwater chair – was originally part of a performance by disabled artist Sue Austin, commissioned for the London 2012 Cultural Olympiad. While Austin's purpose was to show the wheelchair as an object of freedom[1], Brashear's choice of it for the title sequence of Fixed is aimed directly at displacing our preconceived ideas about beauty, normality, disability and impairment.

The film proceeds in four acts of roughly thirteen minutes, each one a collage of formal and on-the-street interviews, family photographs, archival news footage, shots of ordinary city life, and performances by mixed-ability dance troupes. In Act I, we are introduced to the idea of human/machine interaction through interviews with Fernanda Castelo, "test pilot" of an exoskeleton that allows her to walk, and Hugh Herr, a mountain climbing prodigy who lost both legs to frostbite at seventeen. Finding that his prosthetic legs actually made him a better climber, Herr eventually became director of the Biomechatronics Group at MIT's Media Lab, where he leads a research team developing robotic limbs controlled by biological feedback for a variety of activities from the ordinary to the highly specialized. His goal, proclaimed in the film and on the group's website, is a world so technologically advanced it can end disability forever.

While Castelo and Herr both consider their technologies to be fulfilling a normal desire to walk upright and see the world eye-to-eye, Act I also introduces us to Gregor Wolbring, a biochemist and bioethics scholar who sees himself as a normal variant of humanity, disabled but not impaired by being born without legs. Act II moves

[1] http://www.wearefreewheeling.org.uk/

smoothly to explore these divergent definitions of disability and impairment, opening with a dance sequence in which a woman with crutches and prosthetics shaped to look like giraffe legs tries to coax another woman, a non-amputee, to walk using the same crutches and legs. Here Wolbring is shown using a variety of methods for locomotion – his hands and hips, a rolling bar chair, a car, a hand-levered wheelchair. His identity having been built from birth around the body he has, he sees his mobility as limited by his environment, not his body, and vehemently rejects the idea that he needs to be "fixed" by artificial legs. This is juxtaposed against Herr, speaking of "machine beauty in the context of human beauty" over footage of a young male amputee playing soccer and walking on a rocky beach using one of the MIT lab's bionic legs.

While Herr argues that his prostheses are an intrinsic part of both his body and of his identity as someone able to go beyond the human body's natural limitations, activist and artist Patty Berne explains that from a disability rights perspective the problem is not a matter of the body at all, but of social acceptance and provision for people with disabilities, who will always exist, regardless of how far technology is able to go. Futurist writer Jamais Cascio also introduces the idea of extra-ablism through technology in Act II, suggesting that some enhancements are likely to normalize very quickly in some contexts, such as the use of cognitive drugs in higher education, producing a society in which the unenhanced are no longer able to compete with their colleagues on an equal basis, and become in effect disabled by their own normality. Transhumanist James Hughes, however, sees enhancement as producing a world in which all variations and all choices – green skin, gills, wings – are both possible and accepted.

While transhumanism is presented as a philosophy questioning the endpoint of human evolution, Act II also pushes this to the ludicrous, with on-the-street interviews in which one man wishes for pasta coming out of his fingertips, and Hughes hopes for a couple of years looking like Christina Aguilera or maybe Tom Cruise. Act III, however, settles into a more serious exploration of transhumanism and systemic inequalities. Sujatha Jesudason, executive director of Generations Ahead, an organization that works for social justice in the context of human genetics, argues that the theory presumes a form of utopia in which inequality is solved; whereas, it is more likely to reinforce racism when "choice" reflects the physiology of the dominant

group. Meanwhile, as disability rights attorney Silvia Yee notes, there are already 62 million impaired people in the US and longer life spans means this group is more likely to grow in the future than diminish. Berne and Dominika Bednarska, both activist-artists born with their impairments, argue that money should not be invested in high-tech solutions to built-environment impediments, such as wheelchairs that can climb stairs, but on making ordinary electric chairs more reliable, and providing these to those who need them, as well as funding basic healthcare so that fewer people become impaired.

Moving to the other side of this argument, Act III also shows us quadriplegic Tim Hemmes, the first recipient of a multi-million dollar implant which allows him to use his brain to control a robotic arm. Left unspoken is the very real question of whether focusing on the collective distribution of basic mobility tools would in effect dismiss the needs of those like Hemmes, whose impairments are so encompassing that without significant investment into high-tech innovation they would have very little autonomy at all. However, while Hemmes' brain implant reopens the possibility of independent action, it cannot restore his pre-impairment identity in the same way that Herr's specially-designed legs functioned to keep his identity as a world-class climber intact.

In Act IV, we reach the inevitable question of technologies for determining which kind of children are even allowed to be born, bringing the tension between individual and collective needs clearly to the fore. As Berne points out, the story of the search for human perfection also includes systematic extermination of the disabled, however defined at the time, by whatever technology has been available. The Center for Genetics and Society's Marcy Darnovsky argues that on a collective basis, members of groups who are routinely de-selected using reproductive technologies are essentially being told that they are of low value to their society, and as the ability to test embryos for more qualities grows, so too does the expectation of a perfect child. However, she also admits that when offered amniocentesis for her own pregnancy, she accepted it, and would have terminated a fetus with Tay-Sachs disease. Wolbring suggests it is easy to draw a line at such conditions, which cause early death, but where do you draw a line when treatment exists, but is so expensive that most families can't provide it?

Overall, the second half of the film is less about the restorative power of technology and more about the difficulty of balancing very real individual needs with society-changing collective outcomes. Its short concluding sequence does well to recap the frequently oppositional positions of its main interviewees, over half of whom identified in some way as disabled. While the film's strength is in allowing disabled people to speak for themselves, it should be noted that the focus is on mobility, rather than cognitive or sensory impairments. There are also some important questions left unexplored, particularly around the motivation for development and dual-use potential of some ostensibly therapeutic innovations. Although Act II ends with a short montage of soldiers wearing an exoskeleton similar to the one Castilo is piloting, its origin as a project funded by the United States Department of Defense, and subsequent licensing to Lockheed Corporation for further military development[2] is not discussed. Moreover, research on brain implants of the type pioneered by Hemmes has been largely funded by military organizations as the first step towards field applications,[3] opening larger questions about the recruitment of severely disabled people as test subjects for technologies aimed at enhancing healthy users for warfare. There are also questions about the ethics and international legality of using physically and/or neuro-cognitively augmented troops against conventional armies, or even its own citizens. Although it must be conceded that inclusion of these issues may have added a layer of complexity beyond what could be addressed in an already complex hour, some contextualisation would have been useful to clarify that the computer-generated super-soldier footage also used was not entirely science fiction.

Ultimately, however, Fixed is effective not because it answers the questions it poses well, but because it refuses to answer them at all. Although it leans towards a disability rights perspective, it is not a rallying cry for or against technological enhancement. Its strength is in its lack of narration, its juxtapositions of startlingly unexpected images from disability arts – the aquanaut in her wheelchair, the dancers on their giraffe-like prosthetics – to forcefully illustrate the idea that "normal" and "disabled" are categories separable from the bodies to which they're applied. For those familiar with disability scholarship, Fixed also illustrates some of the intrinsic

[2] http://eksobionics.com/ourstory
[3] Van Erp, J., Reschke, S., Grootjen, M., and Brouwer, A (2009) Brain Performance Enhancement for Military Operators. Report prepared for NATO, available from <ftp.rta.nato.int/public/PubFullText/RTO/MP/RTO-MP-HFM-181/MP-HFM-181-32.doc>.

differences between those whose original identity becomes disrupted by illness or accident, and those whose impairment is incorporated into their identity from birth. Rather than reducing the debate to simple polarities, however, it shows the complexity and nuance that arises from personal experience. It also shows that approaching these questions as part of the call to incorporate RI into biomedical innovation will require careful distinctions based upon the nature of the impairment it is intended to "fix" and the technology's position on or inside the body, rather than focusing mainly on its potential for above-normal enhancement. For those unfamiliar with either disability studies or enhancement, the film remains a highly entertaining, as well as visually and intellectually stimulating presentation, making it ideal as introductory material for classroom use. As a way of visualizing and personalizing a difficult, multi-faceted debate, it is highly recommended both to academics and the general public.